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Bridging the divide between epilepsy and mental health to drive solutions[★]

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Abstract

Since its establishment in 2000, *Epilepsy & Behavior* has published more than 1000 papers on mental health issues among people with epilepsy, including about 200 reviews. These studies on prevalence, treatment, and guidance for future research are important contributions to the field, and they offer great promise. Yet these papers and the multitude published in other journals over the years have failed to result in systematic, scaled changes in how the epilepsy field in the United States addresses mental health issues. The mental health assessment and management gap is especially notable given decades-old, as well as more recent, recommendations from national initiatives on epilepsy, consensus statements, and other expert appeals to reduce psychiatric burden. Selected or comprehensive elements of emerging models and latest approaches from behavioral health (e.g., peer support) and public health (e.g., community-clinical linkages) highlight current opportunities to engage multiple community partners and sectors to bridge the epilepsy and behavioral health fields to implement solutions for improved mental healthcare for people with epilepsy. In honor of the 20th anniversary of *Epilepsy & Behavior* and its contribution to the literature and the field, we seek to build public health roadmaps to bridge the epilepsy

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Declaration of competing interest

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and behavioral health divide—with new epilepsy partners who can expand community-based partnerships that may help facilitate systematic changes to close mental health treatment gaps.

Keywords

Mental health; Psychiatric comorbidity; Depression; Intervention; Self-management

1. Introduction

Since its establishment in 2000, *Epilepsy & Behavior* has published more than 1000 papers on mental health issues among people with epilepsy, including about 200 reviews. These studies on prevalence, treatment, and guidance for future research are important contributions to the field, and they offer great promise. Yet these papers and the multitude published in other journals over the years have failed to result in systematic, scaled changes in how the epilepsy field in the United States addresses mental health issues [1].

Some of the most recent reviews in *Epilepsy & Behavior* document the psychiatric burden of specific disorders in epilepsy, their pathophysiology, clinical presentation, treatments, and directions for future research [2–12]. Similar studies were published examining these factors for people with psychogenic nonepileptic seizures [13,14]. Other studies highlight the evaluation of clinical or psychosocial interventions on epilepsy and psychiatric outcomes [15–18]. Additionally, the journal has recently published at least five special issues focused on the neuropsychology of epilepsy and psychiatric burden of epilepsy among children and adults, along with issue editors' calls to action [19–23]. In her overview of *Epilepsy & Behavior* publications on psychosocial topics over a 15-year timeframe, Wagner characterized seminal papers, including a consensus statement on the evaluation and treatment of people with epilepsy and affective disorders, and papers focused on self-management research as some of the unique contributions of the journal [24,25]. Articles identified with one of the journal's tagged features, "From the Managing Epilepsy Well (MEW) Network," describe effective epilepsy self-management programs, correlates of self-management, and reductions in psychiatric symptoms associated with epilepsy self-management programs [26–29]. Nonetheless, noting the "paucity of evidence-based treatments for many psychological conditions for people with epilepsy", Modi et al. provided a guide for the implementation of psychological clinical trials in epilepsy [30].

The mental health assessment and management gap is especially notable given decades-old, as well as more recent, recommendations from national initiatives on epilepsy, consensus statements, and other expert appeals to reduce psychiatric burden (see Table 1) [22,25,31–33]. More than 40 years ago, the former U.S. Department of Health, Education, and Welfare and other epilepsy stakeholders recommended reasonable approaches to address gaps in mental healthcare: that epilepsy groups partner with state mental health agencies to develop integrated and comprehensive mental health services in communities; that mental health professionals receive training in the management of epilepsy; that professionals make referrals to specialized and regular counseling as needed; and that appropriate mental healthcare be monitored (Table 1) [31]. Many of these recommendations from 1977 were

echoed in repackaged formats in 1997, 2003, and as recently as 2012, yet they have generated scant systematic progress [1,32,33].

Commonly known psychological and systems barriers to mental health treatment have been described in this journal and in others—stigma, fear, provider shortages, limited clinic time, and provider reimbursement for psychiatric screening, insufficient evidence on behavioral treatment effectiveness, and insufficient information for patients to help them understand how to advocate for and choose needed mental health treatments [19,20,22,25,26]. These barriers, and some others, including sociodemographic and financial—poverty, poor health literacy, low educational attainment, social isolation, under- or unemployment, insufficient insurance coverage, and out-of-pocket costs—are common to both people with epilepsy and those with behavioral health disorders [34–38]. Selected or comprehensive elements of emerging models and latest approaches from behavioral health (e.g., peer support) and public health (e.g., community-clinical linkages) highlight current opportunities to engage multiple community partners and sectors to bridge the epilepsy and behavioral health fields to implement solutions for improved mental health for people with epilepsy.

2. Public health models or approaches for epilepsy to drive solutions

2.1. Training behavioral health providers

One of the 10 essential public health services in the U.S. public health system is assuring a competent public health and personal healthcare workforce [39]. To increase the number of mental health clinicians who are trained in addressing the mental health needs of people with diabetes, the American Psychological Association and the American Diabetes Association partnered to develop the first diabetes-focused continuing education program for licensed behavioral health providers, the Mental Health Provider Diabetes Education Program (<https://www.apa.org/health/emphasis/diabetes>) [40]. These providers' contact information, and the type of care they provide (e.g., pediatric vs. adult; telemedicine capability) are publicly available in the American Diabetes Association's Mental Health Provider Referral Directory (https://professional.diabetes.org/mhp_listing). Like the diabetes model, a formal training program partnership may begin to address gaps in behavioral healthcare for patients with epilepsy. This joint program could include continuing education credits, joint training opportunities at epilepsy and behavioral health conferences, and an online database of epilepsy-trained behavioral health providers to receive referrals from epilepsy center providers, neurologists, mental health professionals, primary care clinicians, and people with epilepsy.

2.2. Building partnerships with behavioral health entities

The Epilepsy Foundation (EF) initiated, with CDC support, multiple partnerships in 2016, including with the National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD), to train behavioral health providers in epilepsy care. NACBHDD works to improve access to quality behavioral health services locally, especially for the most vulnerable populations. This partnership has developed an epilepsy curriculum for behavioral health providers, led by epileptologists and other epilepsy experts, which includes a webinar series (based on this curriculum) for NACBHDD members and strategies

to expand outreach to other behavioral health providers. Some training of NACBHDD providers began in 2019. Expanding training of NACBHDD providers and other behavioral health professionals, and building partnerships and referral systems with them, could be done regionally and evaluated for any improvements in access to behavioral healthcare for people with epilepsy.

2.3. Building community-clinical linkages

These linkages describe collaborations between healthcare providers in clinical settings, community organizations, and public health agencies to fill gaps in services; promote patient, family, and community involvement; and improve access to preventive and chronic care [41,42]. For example, despite the availability of robust screening tools to identify patients with behavioral health problems such as anxiety or depression, most epilepsy clinics do not use them because of time constraints, lack of reimbursement, and referral barriers [43]. Similar screening and referral barriers exist for other groups. In Los Angeles, a community working group representing primary care providers (the referring physicians), county mental health clinic providers/staff, and parents of children in need of behavioral health treatment identified and intervened on major transition points in the mental health referral and care coordination process when access was most likely to be compromised [44]. Over six months, this group identified three critical points at which a patient might be lost: 1) at the initial referral, 2) at the eligibility and screening process, and 3) at the transfer back to the primary care provider. The group developed “systems solutions” for each transition point—video orientation to the mental health clinic for the patient and family while at the primary care provider location to increase comfort with the facility, a live videoconference session connecting patients in the primary care clinic with mental health clinic staff to conduct screening and eligibility, and regular follow-up videoconferences to connect primary care and county behavioral health providers, so that the former could become more comfortable with treatment follow-up [44]. Six clinics were randomly assigned to intervention or control groups [45]. Participants in the intervention group showed higher levels of completing the initial access screening visit compared with controls (80% vs. 64%) and improved satisfaction with the referral process [45]. But similar proportions (>80%) of the intervention group and the control group accessed treatment once screened. There were no differences in secondary outcomes (e.g., quality of life) among participants in the two groups [45]. As suggested by the Institute of Medicine in its 2012 report on the public health dimensions of the epilepsies, local EF offices, members of the Epilepsy Alliance, the Epilepsy Leadership Council, or other community groups can facilitate such community-clinical links to improve systems of care for people with epilepsy or seizure disorders who need mental healthcare [1]. A community-clinical linkage logic model for epilepsy is attached to provide an overview of the different partners, steps, and activities involved (Fig. 1).

Another example of a successful community-partnership approach to bridge gaps in mental healthcare for people with epilepsy is the Community-Targeted Self-Management for Epilepsy and Mental Illness (C-TIME) program [46]. Originally developed as a CDC Managing Epilepsy Well Network intervention, Targeted Self-Management for Epilepsy and Mental Illness (TIME), this intervention targets adults with epilepsy and comorbid

mental illness, improving their depression outcomes compared with usual care [26]. Notably, TIME was developed collaboratively as a community partnership, among the Ohio Epilepsy Association, people with epilepsy, Case Western Reserve University (CWRU) Prevention Research Center researchers, and other stakeholders [26]. Once TIME was shown to be effective, the Ohio Epilepsy Association, along with the original CWRU investigators, obtained seed funding from the Alcohol, Drug Addiction, and Mental Health Services (ADAMHS) Board of Cuyahoga County, Ohio, U.S.A. to pilot TIME in the community (i.e., “Community-TIME” or “C-TIME”). The ADAMHS board is the lead local public mental health and addiction treatment authority for residents of Cuyahoga County in Cleveland, Ohio. This agency provided modest funding for recruitment, interventionist time, and evaluation [46]. Participants were recruited directly from community settings, neurology clinics, and by electronic health record identification of adults with epilepsy using follow-up program invitation letters. Similar to the pilot, C-TIME showed reductions in depression severity and high patient satisfaction with the program [46]. Sajatovic et al. describe other opportunities for sustainability of this program within the scope of emerging value-based care models and other health transformation opportunities [46]. In its cooperative agreement with the EF, CDC has provided funding to implement effective MEW Network interventions such as TIME, and other programs that target mood disorders and stress management, in community settings [47]. Although participation in these programs is low, efforts are underway to enhance patient and provider awareness of these programs, and providers’ recommendations for these programs where available, in order to increase patient participation rates.

Another innovative community-based solution to address gaps in mental healthcare comes from the EF of Colorado. In 2019, with a modest grant from a local donor, this local affiliate established its own behavioral health preferred provider network encompassing elements previously described—free trainings about epilepsy and other seizure disorders for behavioral health providers, with free continuation education credits for participation; direct referrals from the EF; and a negotiated patient payment and supplemental payment from the affiliate [48]. Evaluation of this intervention is underway.

In 2017, the EF of North/Central Illinois implemented the Program to Encourage Active Rewarding Lives (PEARLS). Designed to eliminate barriers to accessing mental healthcare by using a team-based approach, PEARLS is a home-based treatment program for adults with epilepsy and major, minor, or chronic depression [49]. PEARLS was shown to reduce depression severity and suicidal ideation, and to improve emotional well-being in these adults [49]. Similar to other public health interventions, the PEARLS is designed to be delivered in the community through community-based organizations or social service agencies. Originally developed for older adults, PEARLS programs have been available in multiple U.S. communities through local area agencies on aging [50]. The EF North/Central Illinois affiliate obtained funding from the Housing and Urban Development Community Development Block Grant and the McHenry County (Illinois) Mental Health Board to provide county residents with epilepsy (all-age adults) with mental health support services (personal communication, Nancy Monica, Epilepsy Foundation North/Central Illinois). The PEARLS program in Illinois is a collaboration between the EF North/Central Illinois and the Harvard Senior Center. The EF North/Central Illinois provides referrals to PEARLS,

epilepsy education, and individualized seizure plans for the PEARLS providers. The Harvard Senior Center employs a social worker and case manager who support PEARLS participants with epilepsy. Evaluation of the program in Illinois is ongoing. Epilepsy stakeholders can consider the approach taken by EF North/Central Illinois—partnering with local PEARLS programs for older adults if seeking to expand PEARLS to all age adults with epilepsy in their communities.

People with seizures not only have physical and sometimes mental health symptoms; many describe significant existential concerns related to their future, sense of self, and mortality. The fear of the next seizure is one of the factors rated most likely to affect their quality of life. The bio-psychosocial-spiritual model is used in a growing number of epilepsy centers and allows clinicians to address the whole person in the context of their humanity [51]. Another underused but important community-clinical linkage for people with seizures is partnering with communities of faith, to help address these existential concerns.

2.4. Implementing depression screening

To close behavioral health treatment gaps, in 2018 the EF implemented, with CDC support, depression screening for callers with epilepsy who reached out to the EF 24/7 telephone Helpline (tel: 1-800-332-1000). This Helpline is accredited by the Alliance of Information and Referral Systems and staffed by trained and certified specialists who help callers with their epilepsy needs. Epilepsy Foundation Helpline specialists are trained in and follow the Applied Suicide Interventions Skills Training module, which has been shown to lower the risk of suicide for callers [52].

Following expert input, EF began using the Patient Health Questionnaire (PHQ)-2 as a depression screener, given its brevity and validity [53]. Callers who meet criteria for possible moderate to major depression are asked to contact their primary care physician or epilepsy specialist to discuss this possible diagnosis; those without a healthcare provider are offered referral to a mental healthcare provider. For callers who express suicidal ideation, EF specialists make follow-up calls within 48 h of the initial contact. This follow-up call can significantly reduce suicide risk by providing additional support, referrals, adjusting safety plans, or dispatching emergency interventions, if necessary [54,55]. In a feasibility pilot between May 1, 2018 and October 15, 2018, 51% of adult callers to the EF Helpline who called for a psychosocial or emotional concern were screened (n = 162); of these 24.7% met the criteria for possible depression with 22% of this subgroup expressing suicidal ideation (EF, unpublished data).

The U.S. Substance Abuse and Mental Health Services Administration supports a free, online behavioral health treatment services locator (<https://findtreatment.samhsa.gov>) authorized by the 21st Century Cures Act (Public Law 114-255, Section 9006; 42 U.S.C. 290bb-36d). The Department of Veterans Affairs has a similar Crisis Hotline available to veterans (<https://www.veteranscrisisline.net/>). Epilepsy providers in clinics without capacity for psychiatric screening and referral may consider sharing information about these resources with their patients and encouraging their patients to contact the EF Helpline, local behavioral health services, or local family practitioners equipped to provide mental health services [56].

2.5. Training community health workers

Community health workers are also increasingly used to facilitate community-clinical linkages in chronic disease prevention and management [57]. The use of community health workers to address gaps in behavioral healthcare in primary care shows promise, but their effectiveness in addressing epilepsy care gaps is unknown and ripe for study [58]. The EF implemented a free epilepsy self-management training curriculum developed by CDC (<https://managingepilepsywell.org/chw-curriculum>) for community health workers at two of its local offices in Illinois and Texas. Over 70 community health workers in Texas were trained and reported increased confidence in their ability to coordinate care for people living with epilepsy in their service areas (EF, unpublished data). In the U.S., funding for community health worker programs and research is available from multiple private and public entities, including foundations, federal and state grants (e.g., Centers for Medicare & Medicaid Services State Innovation Model Initiative; Health Resources and Services Administration Behavioral Health Workforce Education and Training Program), and insurance companies [59]. More research on the effectiveness of using community health workers to address gaps in behavioral healthcare for people with epilepsy is needed.

3. Behavioral health approaches for epilepsy to drive solutions

3.1. Integrated care services

Over the past 2 decades, initiatives at federal, state, and local levels have encouraged efforts to integrate behavioral health and primary care services across a continuum, including partnerships such as collaborative care management, colocating services, or full integration within a single care plan [60]. Such initiatives gained more impetus following national healthcare reform in 2010 [60]. Hence, the epilepsy field might consider collaborating with behavioral health entities that support these models of integrated care. NACBHDD can help facilitate related state or local partnerships for the epilepsy and behavioral health fields.

The Philadelphia Veterans Affairs Medical Center (PVAMC) and the University of Pennsylvania developed the Behavioral Health Laboratory (BHL) to identify and intervene on mental health and substance abuse symptoms in VAMC primary care patients [61]. The BHL program provides off-site assessment, monitoring, early intervention, disease management (using an algorithmic approach), and referral management. Trained technicians provide telephone assessments, interpret symptom survey test results, and report results and clinical recommendations to the VA primary care providers. Following improvements in screening and treatment rates, the program was expanded to 30 VA clinics across the country and served as a model for implementation in adult insured populations, federal employee populations, and university populations [61].

The VA Epilepsy Centers of Excellence (ECO) (<https://www.epilepsy.va.gov/>) offer another successful national model of integrated health services. The ECO has established a consortium of epilepsy centers and clinics around the nation to provide care for veterans with epilepsy and the neuropsychiatric comorbidities of seizure disorders. The ECO provides inpatient and outpatient seizure monitoring, neuroimaging, medication, surgery,

neuromodulation, and psychotherapy in clinics and via telehealth to the over 80,000 veterans with epileptic and nonepileptic seizures in the US [62].

3.2. Peer support

Peer support services have grown dramatically in behavioral healthcare over the past two decades. Because peers have direct lived experience with behavioral health conditions, they can be very effective in outreach to people with emerging behavioral health conditions. They also can help new patients negotiate care and provide direct support throughout the care process. Peer support services are an evidence-based mental health model of care and are recognized by the Centers for Medicare & Medicaid Services as an important component in a state's delivery of treatment options and as a billable service for Medicaid recipients [63]. The behavioral health field has developed formal training and certification programs for mental health peer support specialists to ensure that they are qualified to provide appropriate support. Several national nonprofits have worked to develop national certification programs for peers and parent support peers so that they do not need to get recertified when they move to different states [64]. We have an important opportunity to pioneer the use of peers with epilepsy and behavioral health conditions. Trained epilepsy peers have been instrumental in the delivery of effective epilepsy self-management programs [65].

4. Conclusion

During 2010–2017, U.S. adults with epilepsy were almost five times more likely to report serious psychological distress compared with adults without epilepsy [66]. This problematic finding reflects the impact of long-standing barriers and deficiencies in addressing the neuropsychiatric aspects of epilepsy, which have been cogently noted in this journal by previous generations of epilepsy researchers and advocates. As documented in this article, many initiatives have been piloted, tested, and already are underway, and those that have been evaluated have shown success. In a 2019 editorial for the *Epilepsy & Behavior* Special Issue, “Obstacles of Treatment of Psychiatric Comorbidities in Epilepsy,” Dr. Andres Kanner, a luminary in the epilepsy field, asked, “What is wrong with this picture?”, referring to the lack of communication between the epilepsy and behavioral health fields [67]. This communication barrier is magnified by the fact that a number of treatments exist for people with epilepsy, which have demonstrated improved health related quality of life [68], many of them published in the past decade and supported by the CDC's public health efforts to address the issue [69], but are not extensively implemented in the epilepsy community.

In honor of the 20th anniversary of *Epilepsy & Behavior* and its contribution to the literature and the field, we seek to build public health roadmaps to bridge the epilepsy and behavioral health divide—with new epilepsy partners who can expand community-based partnerships that may help facilitate systematic changes to close mental health treatment gaps. Our hope is that for the 50th anniversary issue of *Epilepsy & Behavior*, future authors of a similar commentary will not only describe progress in the widespread implementation of evidence-based approaches, but that they will also ask, “What took them so long?”

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Review

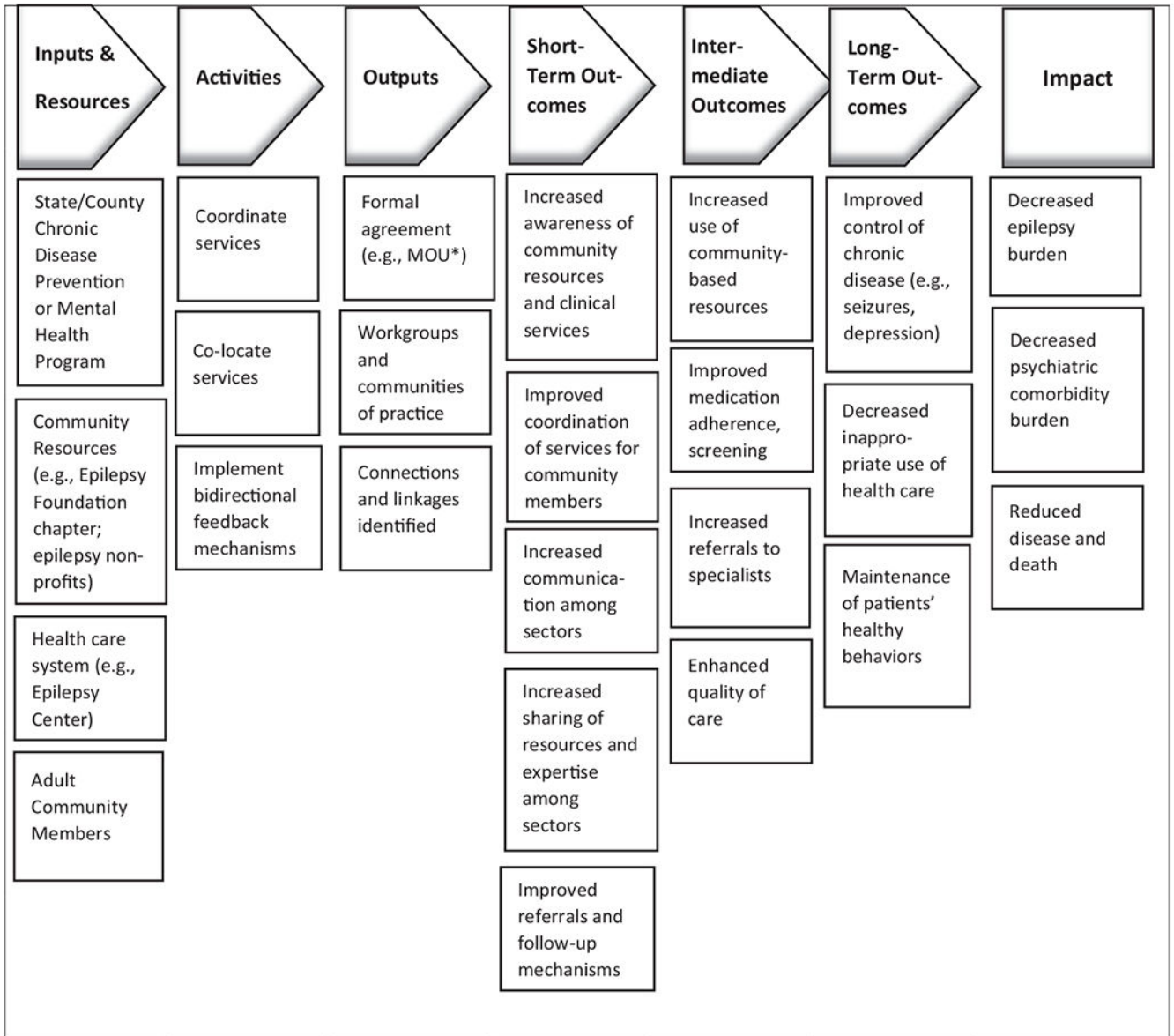


Fig. 1. Community-clinical linkage logic model for epilepsy. *Memorandum of understanding. Modified from: Centers for Disease Control and Prevention. Community-Clinical Linkages for the Prevention and Control of Chronic Diseases: A Practitioner’s Guide. Atlanta, GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services; 2016. Available from: <https://www.cdc.gov/dhds/pubs/docs/ccl-practitioners-guide.pdf>.

Historical recommendations related to improving mental health outcomes in people with epilepsy from the former U.S. Department of Health, Education, and Welfare, *Living Well with Epilepsy I* and *II National Conferences on Public Health and Epilepsy*, and *Institute of Medicine Epilepsy Across the Spectrum: Promoting Health and Understanding—1977–2012*.

Table 1

Plan for Nationwide Action on Epilepsy – 1977^a

- Physicians, local agencies, and individuals providing services to persons with epilepsy should provide counseling to individuals and their families, both on a regularly scheduled basis and as a specific need arises, and should also be prepared to make referrals to specialized counseling and therapy resources as appropriate.
- State mental health catchment area directors, or appropriate agencies, should work with local private agencies and public officials to develop an integrated and comprehensive continuum of mental services within each community, with specific attention to the mental health needs of persons with epilepsy.
- The director of NIMH and state mental health catchment area directors should include in regulations that medical care will be available to persons with epilepsy, as specified in Section 201.B of the Community Mental Health Services Act.
- The Biometrics Division of NIMH and state mental health catchment area directors should collect data on clients with epilepsy served by community mental health facilities to assure that medical care is provided. Further, medical services provided to assist in managing seizures should be entered on each client's record.
- The director of NIMH and state mental health catchment area directors should assure that mental health professionals in community facilities receive training in the management of epilepsy and the unique problems faced by affected individuals.
- The director of the NIMH and state mental health catchment area directors should encourage affiliation agreements between community mental health centers and local groups or agencies providing services to people with epilepsy.
- Local voluntary health groups concerned with epilepsy should monitor the receipt of mental health services to assure that persons with epilepsy are properly served.
- Congress should assure that adequate funds are available to guarantee the provision of adequate counseling and mental health services for those with epilepsy, as recommended by the Commission.

Living Well With Epilepsy I: National Conference on Public Health and Epilepsy – 1997^b

- Epidemiologic research examining the prevalence of psychiatric disorders and symptomatology among people with epilepsy in the community is needed, as is the investigation of the psychiatric sequelae of psychosocial barriers encountered.
- Stigma and the factors that contribute to it should be addressed as the top priority in epilepsy self-management and advocacy.
- Priority target audiences for stigma reduction include the following: school personnel; parents and care givers; healthcare gatekeepers; persons with epilepsy and their care givers
- Advocates for people with epilepsy should take active measures to identify barriers to achieving independence and should actively challenge policies/practices that compromise opportunities for individuals to achieve self-determination.

Living Well With Epilepsy II: National Conference on Public Health and Epilepsy – 2003^c

- Improve the assessment and treatment of the mental health needs of people with epilepsy through professional education and research.
- Establish standards of care for mental health issues in persons with epilepsy, including assessment and care in children.
- Increase the availability of mental health assessments and treatment at comprehensive epilepsy centers and within the public health system.
- Improve access to psychiatric care by building bridges between the mental health and epilepsy community.
- Enhance resources and infrastructure necessary to improve access to social services and enhance quality of life of people with epilepsy.
- Explore strategies to increase access to insurance coverage of mental health and social services for people with epilepsy.
- Train community advocates and specialists to bridge gaps affecting people with epilepsy among public health, community, and healthcare systems.

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- Enhance efforts to develop partnerships among stakeholders in the neurological, disability, and public health communities
- Enhance behavioral and social science research of people “living with epilepsy” and self-management of epilepsy

Institute of Medicine Public Health Dimensions of the Epilepsies – 2012^d

- The CDC, state health departments, and the Epilepsy Foundation, in collaboration with state and local Epilepsy Foundation affiliates and other relevant epilepsy organizations, should partner with community service providers and epilepsy centers to enhance and widely disseminate educational and community services for people with epilepsy that encompass the range of health and human services needed for epilepsy, its comorbid conditions, and optimal quality of life. These efforts should include the following:
 - identifying and disseminating best practices for the coordination of healthcare and community services, including programs using patient and parent navigators, and
 - supporting and expanding efforts by the Epilepsy Foundation’s state and local affiliates and other organizations to link people with epilepsy and their families to local and regional resources, emphasizing active collaboration among affiliates in the same region or with similar interests.

Sources:

^aUS Department of Health, Education, and Welfare. Plan for nationwide action on epilepsy. Bethesda (MD): Public Health Service; 1977.

^bCDC. Living well with epilepsy: Report of the 1997 National Conference on Public Health and Epilepsy. Available at: <https://stacks.cdc.gov/view/cdc/5578>.

^cCDC. Living well with epilepsy II: Report of the 2003 National Conference on Public Health and Epilepsy: Priorities for a public health agenda on epilepsy. Available at: <https://stacks.cdc.gov/view/cdc/5579>.

^dInstitute of Medicine. Epilepsy Across the Spectrum: Promoting Health and Understanding. Washington (DC): National Academies Press; 2012.